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Better the donor you know? A qualitative study of renal patients' views on 'altruistic' live-donor kidney transplantation



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ABSTRACT

Background: In the UK there is a short-fall between individuals requiring a renal transplant and kidneys available for transplantation. Non-directed 'altruistic' living kidney donation has emerged as a strategy for bridging this gap between supply and demand, with the number increasing each year.

Objective: This study aimed to explore the views of potential recipients towards non-directed 'altruistic' live-donor kidney transplantation.

Methods: Semi-structured interviews with 32 UK deceased-donor kidney transplant recipients were performed. Interviews explored willingness to consider directed and non-directed live-donor kidney transplants (LDKTs). Interviews were recorded, transcribed verbatim and transcripts were analysed using the constant comparison method described in Grounded Theory.

Results: For those not willing to accept a non-directed 'altruistic' LDKT, the following themes were identified: i) Prioritising other recipients above self; ii) Fear of acquiring an unknown donor's characteristics, and iii) Concern for the donor – unnecessary risk. For those willing to accept a non-directed 'altruistic' LDKT the following themes were identified: iv) Prioritising known above unknown persons, v) Belief that they are as deserving as other potential recipients, and vi) Advantages of a LDKT.

Conclusions: Drawing on 'gift exchange theory', this study contributes to our understanding of the experience of the intended recipient of a gift. The anonymity of the donor-recipient appears to be seen as a benefit of non-directed 'altruistic' live-donor transplants, freeing recipients from the obligations of the gift. However, those who feel unworthy of the 'gifted transplant' are concerned about the donor and by the lack of opportunity for direct reciprocity. Highlighting the 'reciprocal benefits' reported by donors may allow individuals whose preference is a live-donor transplant to accept one if offered. These insights provide the transplant community with targets for intervention, through which the concerns of potential recipients might be addressed.

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1. Introduction

In the UK in the financial year 2013–2014 approximately 50% of those registered as active on the national kidney transplant waiting list received a deceased-donor or live-donor kidney transplant (NHS Blood and Transplant, 2014). The short-fall between individuals requiring a renal transplant and kidneys available for transplantation is clear. Non-directed 'altruistic' living kidney

donation (also known as 'Good Samaritan', 'anonymous' or 'un-specified' (Dor et al., 2011) donation) has emerged as a strategy for bridging the gap between supply and demand (Sharif, 2013). Non-directed 'altruistic' living kidney donation allows individuals to donate a kidney to an anonymous recipient with whom they do not have a pre-existing emotional link (Human Tissue Authority, 2015). This is in contrast to specified directed living kidney donation, in which a donor donates a kidney to a known recipient, normally a friend or relative.

Much qualitative work has been undertaken to explore renal patients' attitudes towards specified directed live-donor kidney transplantation, summarised in a recent thematic synthesis (Hanson et al., 2015). This research has shown that potential

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recipient concerns regarding live-donor kidney transplantation include feelings of guilt and indebtedness to the donor, a desire not to inconvenience, not wishing to accept a kidney that a family member might need later and concern about the effect of donation on the donor's health, employment, and financial situation (Waterman et al., 2006; Nolan et al., 2004). In addition, a number of studies have explored the motivations and decision making of non-directed 'altruistic' donors (Challenor and Watts, 2013; Clarke et al., 2014; Maple et al., 2014).

To our knowledge no qualitative study has examined the attitudes of renal patients towards non-directed 'altruistic' living donation. As the number of non-directed 'altruistic' transplants performed in the UK increases year on year (NHS Blood and Transplant, 2014), it is important that patients' views about this treatment option are evaluated.

This study aimed to gain an in-depth understanding of the beliefs and feelings of potential recipients about non-directed 'altruistic' living donation and transplantation, and their willingness to accept such a transplant if it were offered. We also aimed to compare these findings with an individual's thoughts about directed live-donor kidney transplantation. We aimed to identify barriers and facilitators to the acceptance of a non-directed 'altruistic' live-donor kidney transplant (LDKT).

2. Materials and methods

The Consolidated criteria for reporting qualitative studies (COREQ) (Tong et al., 2007) was adhered to.

2.1. Participant selection

Participants were eligible if they had received a deceased-donor renal only transplant at the regional transplant centre Southmead Hospital, North Bristol NHS Trust, UK between 1/8/08 and 31/7/13. Deceased-donor transplant recipients were selected as individuals medically fit for transplantation but who had either been unable to identify any living donors, had declined offers from potential living donors, or had recruited donors who had not completed clinical assessment or had been unable to donate to their known recipient. These individuals were therefore the most likely to have been offered a non-directed 'altruistic' LDKT were one to become available. Purposive sampling was used to select interviewees, aiming for maximum diversity in terms of age, gender, ethnicity, socioeconomic position, employment status, primary renal disease, and previous renal replacement therapy modality. The English Index of Multiple Deprivation (IMD) 2010 score was used as a measure of socioeconomic deprivation at the small area level, derived from postcode data (Noble et al., 2006; Payne and Abel, 2012). IMD scores are nationally divided into five population quintiles according to the level of deprivation of the output area to which they belong. The fifth quintile represents the greatest deprivation. Sample size was determined by reaching theme saturation, when few or no new concepts were emerging (Tong et al., 2014; Morse, 2015). All individuals invited were over 18 years of age with the capacity to give consent to participation.

The study was approved by NHS Research Ethics Committee South East Coast – Surrey in December 2013 (Reference 13/LO/1820).

2.2. Data collection

Individuals were invited to participate by post with a letter from the renal consultant responsible for their care. Non-responders were sent two reminder letters. Invitations were staggered, but in total 61 individuals were invited. 32 (52%) agreed to participate.

Reasons for non-participation were not explored. Between February 2014 and May 2015 a face-to-face semi-structured interview was conducted with each participant at the hospital. Participants were interviewed after their routine transplant clinic appointment for their convenience. The interviews were conducted by the first author PB, who was working as a full-time doctoral researcher at the time of the study. PB had previously worked as a doctor at the hospital, and had been involved in the ward based and outpatient care of six of the thirty-two participants. Participants provided written consent. All participants were able to speak English fluently and therefore translators were not required. Six individuals requested that a family member be present for the interview. Interviews investigated participants' perceptions of live-donor kidney transplantation and their experiences (if any) of trying to recruit living donors. Beliefs about both directed and non-directed 'altruistic' living kidney donation and transplantation were explored. Participants were asked to recall their thoughts about live-donor kidney transplantation at the time they had been considering renal replacement options. Participants were also asked to consider the future were their current transplant to fail, and their attitude to being offered a non-directed 'altruistic' LDKT. A flexible topic guide was employed to ensure that the main questions were discussed with all respondents. The topic guide is available as Supplementary Data. Interviews lasted between 18 and 72 min. Interviews were digitally audio-recorded, transcribed verbatim and anonymised.

2.3. Data analysis

Recordings were listened to and transcripts read twice for familiarisation. NVivo qualitative software was used to aid analysis. Sections of text of the transcribed interviews were coded by assigning descriptive labels, and codes were grouped on the basis of shared properties to create concepts, then categories, then themes, using the constant comparison method described in Grounded Theory (Glaser and Strauss, 1967; Miles and Huberman, 1984). All transcripts were coded by the first author (PB). A subset of interviews was independently analysed by another experienced qualitative researcher and co-author (AOS), and coding discrepancies discussed to maximise rigour and reliability. Themes were identified and analytic induction used to identify any patterns arising.

All illustrative quotations were approved by study participants prior to publication.

3. Results

32 (52%) of 61 invited individuals agreed to participate (Table 1: Participant characteristics). Non-participant characteristics are available as supplementary material (Supplementary Material – Non-participant characteristics).

3.1. General attitude to non-directed 'altruistic' live donors

Overall, regardless of willingness to accept a non-directed 'altruistic' LDKT interviewees described non-directed 'altruistic' donors very positively. No individuals expressed concern regarding donors' motives, all assuming such individuals had only good intentions:

"The person coming in off the street is absolutely a wonderful person." (Interviewee 8)

"I think these people are utterly amazing." (Interviewee 13)

"Yeah, I think they're remarkable basically." (Interviewee 27)

Table 1
Participant characteristics.

Characteristics	Number	%
Sex		
• Female	17	53
• Male	15	47
Age group (years)		
• 21–40	4	13
• 41–60	15	47
• 61–80	13	41
Ethnicity		
• White	29	91
• Non-white	3	9
Renal replacement therapy prior to transplantation		
• None (CKD 4/5)	2	6
• Peritoneal Dialysis	10	31
• Haemodialysis	16	50
• Peritoneal Dialysis and Haemodialysis	4	13
Primary renal disease group		
• Glomerular disease	8	25
• Tubulointerstitial disease	6	19
• Systemic disease affecting the kidney	3	9
• Familial/hereditary nephropathies	8	25
• Miscellaneous renal disorders	7	22
Index of multiple deprivation quintile		
• 5 (most deprived)	6	19
• 4	13	41
• 3	5	16
• 2	2	6
• 1 (least deprived)	6	19

3.2. Willingness to receive a non-directed 'altruistic' LDKT

Individuals could be categorised into four mutually exclusive groups according to their willingness to receive a non-directed 'altruistic' live-donor transplant (Table 2: Willingness to receive directed and non-directed 'altruistic' live-donor kidney transplants):

i) those willing to accept a LDKT from any living donor, ii) those willing to accept a specified directed LDKT only, iii) those willing to accept a non-directed 'altruistic' LDKT only, and iv) those not willing to accept an LDKT from any type of live-donor.

Six different themes emerged, clustered into two groups depending on the participants' willingness to receive a non-directed 'altruistic' LDKT. For those not willing to accept a non-directed 'altruistic' LDKT, the following themes were identified: i) Prioritising other recipients above self; ii) Fear of acquiring an unknown donor's characteristics, and iii) Concern for the donor – unnecessary risk.

For those willing to accept a non-directed 'altruistic' transplant the following themes were identified: iv) Prioritising known above unknown persons, v) Belief that they are as deserving as other potential recipients, and vi) Advantages of a LDKT. Selected quotations to illustrate each theme are provided in Table 3: Themes and illustrative quotations.

Table 2
Willingness to receive directed and non-directed 'altruistic' live-donor kidney transplants.

	Willing to accept a LDKT from a non-directed 'altruistic' donor	Not willing to accept a LDKT from a non-directed 'altruistic' donor
Willing to accept a LDKT from a known specified directed living donor*	15 interviewees	4 interviewees
Not willing to accept a LDKT from a known specified directed living donor	9 interviewees	4 interviewees

LDKT = Live-Donor Kidney Transplant.

*in at least some circumstances.

3.3. Not willing to accept a non-directed 'altruistic' live-donor kidney transplant

Eight individuals reported not being willing to accept a non-directed 'altruistic' LDKT. For four individuals this decision was a reflection of their decision not to accept a transplant from any living donor, but for the other half specific issues with respect to non-directed 'altruistic' donation were described.

3.3.1. Prioritising other recipients above self

Participants expressed a preference for another person receiving the non-directed 'altruistic' live-donor transplant over themselves. Some participants expressed a belief that they were not worthy of a non-directed 'altruistic' transplant; describing a desire to have a live-donor transplant, but stating that other individuals were more deserving than them:

I = Interviewee R = Researcher

I: It would be lovely to have the [non-directed 'altruistic'] living but I probably wouldn't do it.

R: Mm, and why, what would stop you?

I: Because somebody else is more worth it than me.

R: ...even though it's going to go anyway, to anybody?

I: Yeah but that person would be better than me.

R: In what sense 'better'?

I: A nicer person. (Interviewee 13)

3.3.2. Fear of acquiring an unknown donor's characteristics

Whilst many individuals perceived it as positive that a non-directed 'altruistic' donor was a stranger, this was not universal. One individual, who reported being willing to accept a specified directed transplant from a friend or family member but not from a non-directed 'altruistic' live-donor, described in detail her concerns regarding non-directed 'altruistic' donation. She reported holding a belief that some of the living donor's characteristics are transferred to the recipient on transplantation, and that if the donation was non-directed 'altruistic' she as the recipient wouldn't be able to judge whether the donor is someone from whom she'd be happy to receive. This individual didn't have the same beliefs regarding receiving a kidney from an unknown deceased-donor.

3.3.3. Concern for donor – unnecessary risk

Many participants expressed concern for the non-directed 'altruistic' living donors, and for some this was the reason they were unwilling to accept a non-directed 'altruistic' LDKT. Participants described feeling responsible for the risks donors would be exposed to, and anticipated feeling guilty. Some individuals suggested that if they declined an offer of a non-directed 'altruistic' transplant, then the donor may not go on to donate. Thereby the intended recipient could protect the non-directed 'altruistic' donor from risk.

Table 3
Themes and illustrative quotes.

	Theme	Illustrative quotations
Not willing to receive a non-directed 'altruistic' live-donor kidney transplant	Prioritising other recipients above self	"The person coming in off the street is absolutely a wonderful person to do that but I would be quite happy to take the deceased- ... I mean let somebody have the living donor." (Interviewee 8) "It would be lovely to have the living but I probably wouldn't do it. Because somebody else is more worth it than me." (Interviewee 13) "I would actually say- I think I would still go for the deceased-because then that one would be still there waiting for somebody else who perhaps wasn't ready for- able to take the deceased one." (Interviewee 30)
	Fear of acquiring an unknown donor's characteristics	"If...you didn't really know anything about the people that had donated and been passed on...but it's not knowing anything about it, you know. You don't know anything about that person. Well don't they say sometimes you change to that person? Things can happen to that person to you, from a kidney, um, so you know, things like that. It goes through your mind." (Interviewee 10)
	Concern for the donor – unnecessary risk	"No I couldn't deal with it. No I would always sit down and think 'Is that person still alive?' or is, you know 'Is that person alright?' no I couldn't do it." (Interviewee 3) "I'd pick [a] deceased [over an offered unspecified living transplant]. Because that person wouldn't have to go- I've been in hospital so much in my life ... and it's been a part of my life for sadly twenty years (laughs) (pause) why someone would want to ... why would you want to come in hospital for someone to have surgery and stay in and- when there's a [deceased] kidney that you could make the most of." (Interviewee 14)
Willing to receive a non-directed 'altruistic' live-donor kidney transplant	Prioritising known above unknown persons	"I just feel- again it's just having that guilt thing I suppose." (Interviewee 30) "I'd probably (pause) save her [potential donor relative] from the operation and choose the other one [unspecified], if they're willing to do it." (Interviewee 16) "It would be an option to definitely think about. Definitely because- it sounds really bad but it's- I don't have that bonding connection. It's not a family member. Not to say that I wouldn't care if something happened to them (pause) but they don't have the pressure of it being a loved one and it's something they want to- an amazing thing that they want to do and it's completely their choice and there's no pressure so I think already I could probably say yeah." (Interviewee 17) "As it was donated freely, I wouldn't feel anything about taking [an altruistic donor kidney transplant]. As would a dead kidney that's given freely too by donation and again I feel free about that. But to hinder a living, say brother or family member, to not being able to help theirs in need was just too much to accept." (Interviewee 20)
	Belief that they are as deserving as other potential recipients	"I suppose- I mean I suppose if I was really sick and not working then (sighs) and that person's going to donate anyway, doesn't matter if I have it or someone down the road has it-then I might possibly. Possibly." (Interviewee 11) "I would presume yes. You know, if I was that position I would imagine yes. Especially if, you know, sort of, the kidney is already out of him or her, that's why, you know, what's the use of wasting a kidney if it's already been taken out. So..." (Interviewee 2)
	Advantages of a live-donor kidney transplant	"Well if the kidney hasn't, um, if the person carrying the kidney hasn't died there's less chance- When from a living person I think the kidney has more of a chance of surviving. That would be my point- that would be my thinking sitting here now..." (Interviewee 18) "[I'd take] the living one, and I- the reason why is I assume, although I've been told the difference isn't that much, that they're going to live longer, it's going to be more, you know, it hasn't had a period of not being properly active, you know, not- That's my assumption-" (Interviewee 16) "...a living one will always be better won't it?" (Interviewee 22)

Participants' unwillingness to accept a non-directed 'altruistic' LDKT due to concerns regarding the donor was often accompanied by the belief that the risks to the donor were unnecessary when there were already deceased-donor kidneys available that recipients 'could make the most of'. Individuals expressed the belief that other sources of kidney transplants should be exploited first before putting living donors at risk.

3.4. Willing to accept a non-directed 'altruistic' live-donor kidney transplant

Most participants (24 individuals) reported being willing to accept a non-directed 'altruistic' LDKT. For those willing to accept a non-directed 'altruistic' transplant the following themes were identified:

3.4.1. Prioritising friends/relatives above unknown persons

Participants perceived accepting a non-directed 'altruistic' donor kidney as a way of protecting friends or relatives, who might have offered to donate, from the risks of donation. Most

participants felt that it was easier to accept a transplant from a stranger than someone they knew. Many participants described how they wouldn't feel responsible for the donor or guilty regarding the risks they were taking.

3.4.2. Belief that they are as deserving as other potential recipients

Individuals reported that if a non-directed 'altruistic' donor has made the decision to donate, and the kidney is going to go to someone, then they are as deserving as anyone else. Participants often expressed this as a conclusion they had arrived at reluctantly or hesitantly:

"I suppose- I mean I suppose if I was really sick and not working then (sighs) and that person's going to donate anyway, doesn't matter if I have it or someone down the road has it- Then I might possibly. Possibly." (Interviewee 11)

3.4.3. Advantages of a LDKT

Many participants explained that their enthusiasm for a non-

directed 'altruistic' live-donor transplant resulted from having no personal donors but recognising the advantages of LDKTs over deceased-donor transplants. These advantages were described in terms of recipient and graft survival.

Recognising these benefits, one individual described her belief that 'recruiting' potential 'altruistic' donors using the media and social media was likely to become increasingly common which would increase the number of such transplants occurring:

"I think to be honest it's got to be the way forward because the generations differ, there's a big difference whereas for my generation you don't feel you can ask ... whereas nowadays, you know, like my children's generation they're getting a bit more brash and a bit more, you know, 'Oh I need this, who's going to give me a kidney then?' and before you know it it's gone viral and ... I think in a way that will produce more kidneys because people will think about it, you know. I think that would produce more, definitely." (Interviewee 12)

4. Discussion

To our knowledge this is the first qualitative study to describe potential recipient beliefs and thoughts about non-directed 'altruistic' live-donor kidney transplantation. We have identified attitudinal barriers and facilitators that contribute to a recipient's willingness to accept a non-directed 'altruistic' LDKT.

Previous research has explored the attitudes of the 'general public' (Spital, 2001; Landolt et al., 2003) to non-directed 'altruistic' living donation. In the USA, non-directed 'altruistic' live-donor kidney transplantation appeared to be acceptable to the majority (80%) of those surveyed from the general population. Furthermore, approximately 25% of those surveyed in the USA and Canada reported being willing to consider being a non-directed 'altruistic' living donor.

A few studies have explored the motivations and attitudes of non-directed 'altruistic' living kidney donors themselves (Nolan et al., 2004; Challenor and Watts, 2013; Clarke et al., 2014). Non-directed 'altruistic' living donors, much like specified directed donors, express prosocial motives, a compelling desire to donate and recognise personal psychosocial gains. Non-directed 'altruistic' living kidney donors in the UK are an active group, who promote the option of being such a donor using the internet and media (Give a Kidney – One's Enough – Registered Charity, 2015), aiming to encourage more people to consider donating in this way.

However, research evaluating the attitudes of renal patients towards non-directed 'altruistic' live-donor kidney transplantation has been lacking. A discrete choice experiment from the USA found that for patients, the preferred source for a LDKT was a family member or close friend, followed by paired kidney exchange over an anonymous non-directed 'altruistic' donor (Davison et al., 2010). Our study expands on this finding, describing the range of different attitudes to non-directed 'altruistic' donation by potential recipients, and the beliefs behind these positions.

5. Receiving and gift exchange theory

The 'gift exchange' theory has long been applied to organ transplantation (Fox and Swazey, 1978; Simmons et al., 1987). In his essay on 'The Gift' Mauss (1954[1925]) identified three stages to gift exchange: giving a gift; accepting or receiving a gift; and repaying a gift. He described how gifts 'are never completely separated from the men [sic] who exchange them.' This bond between giver and gift creates a social bond between giver and receiver. The act of

giving creates debt which must be repaid, compelling reciprocity. This study contributes to our understanding of the complexities around receiving a 'gifted' transplant.

Receiving may be the most complicated part of gift exchange, which the varied and complex ideas expressed in this study reflect (Lamanna, 1997). There are numerous historical examples of refusal or reluctance to accept help offered in the form of welfare (Briar, 1966), unemployment assistance (Goodwin, 1972) and aid to Third World nations (Gergen and Gergen, 1974). Receiving help has been associated with feelings of manipulation, relinquishing power and control and reduced self-esteem (Lamanna, 1997). Sharp (1995) argued that 'transplants create new ... social relationships that affect how organ recipients assess their own social worth.' Many participants in our study expressed a sense of being 'unworthy' of a transplant, suggesting that 'worth' and self-esteem influence an individual's decision to accept a non-directed 'altruistic' live-donor transplant. Feeling undeserving of a transplant has previously been reported amongst older renal patients who felt they had already 'lived a full life' (Gordon, 2001). As the majority of our participants were younger, it is possible that the size of the apparent gift and the inability to repay it contributed more to the sense of being undeserving than their age. As the anonymity of the donors and recipients are usually preserved in the UK the opportunity for such a transplant recipient's direct reciprocity is compromised.

In previous qualitative studies of renal patients' attitudes to live-donor kidney transplantation from a known donor, participants reported reciprocal benefits for donors, such as increased self-esteem from helping a loved one (Mazaris et al., 2012; Hanson et al., 2015), or alleviated caregiver burdens and improved quality of life in a spouse or partner. Many participants in our study expressed concern for an anonymous live donor and desired to protect them from donating. However, some of these participants were willing for friends and relatives to be living kidney donors, suggesting that the risks and experience of donation are perceived as balanced (at least to some extent) if the donor is known to the recipient, and is seen as benefitting in some way from the donation experience. Accordingly, research has indicated that help is more accepted in mutually supportive ongoing relationships (Fisher et al., 1981; Clark, 1983), including the specific case of live-donor kidney transplantation (Franklin and Crombie, 2003).

The socialized person has a sense of equity and reciprocity, and that one should reciprocate gifts or deeds done for one's benefit (Mauss, 1954[1925], Walster et al., 1973, 1978; Gouldner, 1960). Difficulties arise if no possibility exists for a gift's repayment, an issue expressed by many deceased-donor recipients who wish to reciprocate the gift in some way (Schweda et al., 2009). This feeling may be all the more so when the donor is still alive as in 'altruistic' live-donor transplantation. If offered the choice of receiving a deceased-donor transplant or an 'altruistic' live-donor transplant, many participants in our study said they would prefer another person on the waiting list to receive the non-directed 'altruistic' LDKT. It is possible that this is because they do not want to be so indebted as they would be by receiving a non-directed 'altruistic' LDKT, or that they feel unworthy of such a transplant 'gift'. Alternatively this sentiment might be an attempt to reciprocate in some way, at least to 'society' if not directly to the individual donor, by allowing another renal patient to receive the transplant associated with the best survival. The way participants in our study framed their decision suggests not a lack of recognition of the potential benefits of a live-donor transplant, but rather wanting to 'gift' it to someone else: *"The person coming in off the street is absolutely a wonderful person to do that but I would be quite happy to take the deceased- ... I mean let somebody [else] have the living donor."* (Interviewee 8)

5.1. Anonymity

Several of our study participants reported that lack of knowledge about the donor was a barrier to accepting an 'altruistic' donor transplant because it was unclear what impact donation would have on the donor. Individuals wanted reassurance that a donor would not have been harmed by donation: *"No I couldn't deal with it. No I would always sit down and think 'Is that person still alive?' or is, you know 'Is that person alright?' no I couldn't do it."* (Interviewee 3).

Most of our study participants perceived the anonymity of donor–recipient as a positive aspect of 'altruistic' kidney transplantation. It was viewed as protecting the donor from pressure or coercion to donate, and released the recipient from feeling controlled or manipulated by the donor (Kranenburg et al., 2005). Thus, the imposed anonymity in non-directed 'altruistic' live-donor transplantation is seen by many participants as a way of defying or avoiding the obligations of the gift. Similar findings are reported from interviews with individuals undergoing fertility treatment using donated gametes (Blyth et al., 2013; Sawyer et al., 2013; Frith et al., 2012), who do not want the donor to interfere with their life through access rights to their child.

However, in both organ transplantation (Annema et al., 2015) and the receipt of donor gametes (Blyth et al., 2013; Sawyer et al., 2013; Frith et al., 2012), this desire for wanting to be free from manipulation and interference appears to be held in combination with a desire for at least some knowledge about the donor. The themes emerging from our study illustrate similar positions amongst renal patients: both a recognition of the possible benefits of anonymous donation due to the lack of manipulation within the donor–recipient relationship, as well as concerns about having no information about a donor.

One participant in our study reported that a specific lack of information about the donor's personality and characteristics would stop her from accepting an anonymously donated live-donor organ. This participant described being worried about acquiring an unknown donor's (negative) characteristics, believing that a recipient becomes like the donor through receipt of their organ. This idea has been well described (Sharp, 1995; Gordon, 2001; Sanner, 2001; Beidel, 1987; Hood et al., 2011) as 'contamination', 'the influencing organ' (Sanner, 2001) and 'moral contagion' (Hood et al., 2011). As in Sanner's work (Sanner, 2001), our participant did not describe a mechanism of 'inheriting' characteristics but reported that she had heard this not uncommonly held notion described by others: *"Well don't they say sometimes you change to that person?"* (Interviewee 10)

Psychologists and medical sociologists have postulated various theories to account for the sensations many transplant recipients report that they have inherited a donor's characteristics. Some psychologists have presented such experiences as evidence of 'cellular' or 'systemic memory' (Pearsall et al., 2000), whilst others have described these as 'incorporation fantasies' (Bunzel et al., 1992) or examples of 'magical thinking' (Vamos, 2010). Magical thinking is used to describe a belief that causal relationships exist between actions and event, which seemingly cannot be demonstrated or proven by scientific observation (Vamos, 2010; Keinan, 1994). Key to magical thinking with respect to transplantation is the concept of psychological essentialism, the notion that individuals treat objects and entities in the world as if they have an underlying core nature or "essence" that determines the properties and characteristics of that object or entity (Medin and Ortony, 1989). The essence or symbolic weight of the organ appears to be related to the degree and likelihood of transformative experiences (Sharp, 1995). Sharp (1995) has described that such experiences associated with heart and lung transplants are generally more

serious than those involving kidneys because the former are 'loaded with more powerful metaphors that define what it means to be human and alive.' Interestingly, these feelings had not prevented our study participant accepting a deceased-donor transplant organ, suggesting that death reduces the perceived potency of transferring a donor's traits through an organ, or if dialysis is the only alternative even the non-preferred transplant becomes acceptable. Similar ideas have been reported as felt by the families of deceased organ donors, who believe, and may be encouraged to believe, that their relative 'lives on' in the recipient: *"She wants to get together sometime, but I don't think I want to meet her, though. She thinks that her husband lives on in me; but I feel uncomfortable about that -"* (Sharp, 1995).

However, the majority of our participants were not concerned about being changed by a donor organ. Perhaps this is because most renal transplant recipient candidates have had a long history of dialysis and so have learnt to objectify the body as a biological entity separate from self, and thus might adjust more easily to the concept of transplantation (Belk, 1990). Anthropologists have documented how biomedicine reinforces this objectification of the body especially in transplant surgery (Featherstone, 1982; Featherstone and Turner, 1995; Williams, 1997). In addition, research with transplant recipients has suggested that choosing not to focus on the donor of the organ, certain aspects of the donor's life and/or their death (described by some commentators as 'denial' of the donor) can serve a protective and adaptive function (Mai, 1986; Sanner, 2003).

Several participants reported that it would be easier to accept an anonymously donated LDKT than one from a friend or relative, because they would feel less responsibility for the donor's actions and less 'guilt'. Qualitative research with deceased-donor recipients has suggested many feel similarly free from any responsibility regarding the donation: *"When I made myself think about it, I thought, 'Well, he's dead. I didn't hurt him. I didn't cause him to die.'"* (Siminoff and Chillag, 1999) This suggests that some individuals find it easier to receive an organ transplant when they are 'free' from the obligations of gift exchange.

5.2. Donor gains

No participant commented on the potential positive impact of donation on the donor. The families of deceased organ donors have reported being motivated by a desire to help others so that the death of their relative accrues meaning, and their loved ones can live on in the recipient (Siminoff and Chillag, 1999). This is similar to the motivations expressed by living non-directed 'altruistic' donors for whom the desire to donate has been reported as 'compelling' (Nolan et al., 2004), and donors experience the donor identity of feeling good and feeling connected (Challenor and Watts, 2013). 'Altruistic' donors have reported rejecting personal motivations for non-directed 'altruistic' donation, and instead detail their psychological motives and gains (Nolan et al., 2004; Challenor and Watts, 2013). The positive feelings donors receive from donation could themselves be seen as the 'reciprocal gift', received by the very act of donating. For those renal patients who struggle with the burden of the transplant 'gift', highlighting the benefits experienced by donors may allow individuals whose preference is a live-donor transplant to accept one if offered.

6. Interventions and impact

A number of therapeutic approaches to improve an individual's self-worth and confidence (Fennell, 2004; Waite et al., 2012; Dixon, 2008), could be trialled with specific individuals who perceive themselves as being undeserving of a non-directed 'altruistic' LDKT.

The impact of increasing self-worth and confidence on an individual's willingness to receive a non-directed 'altruistic' LDKT could then be assessed.

Discussion and dialogue between potential recipients and the vocal non-directed 'altruistic' donor community (*Give a Kidney – One's Enough – Registered Charity, 2015*), and existing recipients, should be encouraged and facilitated. Communication with non-directed 'altruistic' donors enables renal patients to be given accurate information on the process of non-directed 'altruistic' donation, and explanation that declining an offered non-directed 'altruistic' kidney transplant does not stop that individual donating. Meeting non-directed 'altruistic' donors may also allow patient fears regarding anonymous donors to be assuaged, and intended recipients may be able to appreciate the psychological benefits 'altruistic' donors report experiencing following donation (*Nolan et al., 2004; Challenor and Watts, 2013*).

Finally, renal patients do not need to be passive whilst awaiting a transplant. As raised by one of the study participants, individuals can attempt to actively recruit an 'altruistic' living donor, using advertisements. The Human Tissue Authority in the UK defines this as 'directed altruistic donation', in which i) the donation is being directed to a specific individual and ii) there is no evidence of a qualifying genetic or pre-existing emotional relationship between the donor and recipient (*Sharif, 2013*). For those who desire knowledge about the 'anonymous donor' the possibility of 'directed unspecified donation' might allow them to pursue the option of unspecified donation and transplantation.

A failure on behalf of the clinical team to adequately inform individuals about the option of 'altruistic' live-donor transplantation is a failure to adequately empower an individual to pursue a transplant. Therefore, clinicians must ensure wait-listed individuals are aware of the possibility of, are equipped with accurate information on, and fully understand the process of 'altruistic' live-donor transplantation. Live-donor kidney transplantation offers the best treatment in terms of life-expectancy and quality of life for most people with advanced renal disease (*Maple et al., 2014; Cecka, 1995; Laupacis et al., 1996; Cecka, 2005*). Addressing barriers to 'altruistic' live-donor kidney transplantation is important to ensure that individuals are not prevented from receiving an 'altruistic' kidney because of a lack of information, a lack of self-worth, or a lack of appreciation of the potential benefits to donors. 'Altruistic' kidney transplantation allows individuals who lack suitable live-donors amongst their friends and family to experience the benefits of a LDKT, but removing barriers to receiving such a transplant has the potential for greatest impact in the context of enabling a donor chain. If an individual has a potential specified directed live-donor who is not an acceptable match (and alternative options such as desensitization are unavailable or unacceptable) then overcoming barriers to one individual accepting non-directed 'altruistic' donation may allow multiple transplants to happen instead of one (*Melcher et al., 2013*).

Non-directed 'altruistic' kidney transplantation is not acceptable to all recipients. In addition, individuals do not hold a single universal attitude to live-donor kidney transplantation as some participants reported being willing to accept a LDKT from a friend or relative but unwilling to receive a transplant from a stranger, and the reverse. In clinical practice, no assumptions should be made regarding an individual's readiness to accept a non-directed 'altruistic' live-donor transplant but rather that individual's preferences should be explored in detail, along with reasons for their position.

6.1. Limitations

This study provides an in-depth investigation of renal patient

attitudes to non-directed 'altruistic' live-donor transplantation. Theme saturation was reached, and participants were purposively selected for maximum diversity to capture the attitudes of a variety of transplant recipients. There are however a couple of limitations to the study. This was a single-centre study from a UK transplant centre which serves a predominantly white population. There were few non-white participants ($n = 3$), therefore findings might not be transferable to other populations in other health systems or other ethnic groups. Individuals were asked to reflect on a hypothetical scenario of being offered a non-directed 'altruistic' kidney transplant, rather than comment on a current real-life decision. However, most of the individuals interviewed were aware that they may need to consider transplant options again in the future, following possible current graft failure so the scenario is not overly contrived. All participants were recipients of deceased-donor kidney transplants, and therefore represent a sub-section of the 'transplant population'. It is important to ascertain whether similar findings emerge from interviews with individuals on the transplant waiting-list and recipients of LDKTs.

7. Conclusions

We have identified barriers and facilitators to a recipient's acceptance of a non-directed 'altruistic' live-donor transplant. Drawing on 'gift exchange theory', this study contributes to our understanding of the experience of the intended recipient of a gift. The anonymity of the donor-recipient appears to be seen as a benefit of non-directed 'altruistic' live-donor transplants, freeing recipients from the obligations of the gift. However, for those who feel unworthy of the 'gifted transplant', are concerned about the donor and by the lack of opportunity for direct reciprocity, highlighting the 'reciprocal benefits' reported by donors may allow individuals whose preference is a live-donor transplant to accept one if offered. These insights provide the transplant community with possible targets for intervention through education and facilitated discussions between potential recipients and the active community of non-directed 'altruistic' donors, through which the concerns of potential recipients might be addressed. As the number of non-directed 'altruistic' transplants increases year on year (*Maple et al., 2014*), it is important that barriers to individuals receiving a non-directed 'altruistic' transplant are identified and minimised, to ensure equal access to and ready uptake of this valuable resource.

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Appendix A. Supplementary data

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